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Citation for published version:

Richardson, A, Addington-Hall, J, Amir, Z, Foster, C, Stark, D, Armes, J, Brearley, SG, Hodges, L, Hook, J, Jarrett, N, Stamataki, Z, Scott, I, Walker, J, Ziegler, L & Sharpe, M 2011, 'Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review', *British Journal of Cancer*, vol. 105, pp. S82-S94. <https://doi.org/10.1038/bjc.2011.425>

Digital Object Identifier (DOI):

[10.1038/bjc.2011.425](https://doi.org/10.1038/bjc.2011.425)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

British Journal of Cancer

Publisher Rights Statement:

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Full Paper

Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review

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BACKGROUND: Patients who have completed initial cancer treatment (cancer survivors) have been relatively neglected. We need data to help us better understand the needs of this group and to underpin evidence-based service development.

METHODS: Scoping reviews of research published in the last two decades focussing on the problems faced by cancer survivors, and the effectiveness of interventions for these problems were undertaken. The aim was to identify what we know, what we do not know and opportunities where research could provide new information. We searched for, retrieved and rapidly appraised systematic reviews sourced from the most common electronic databases supplemented by more recently published individual studies.

RESULTS: The research evidence is surprisingly limited. We have some knowledge of the prevalence and nature of depression, pain and fatigue in cancer survivors. We know much less about cognitive and physical impairment, employment, financial well-being and relationships. Even where we have evidence, it is mostly of only moderate quality, is most often only for breast cancer and focuses almost exclusively on the early phase of survivorship. We have good evidence for the effectiveness of drug treatments for pain and moderate evidence for fatigue and depression, but not for other symptoms. Interventions based on rehabilitative and self-management approaches remain in the early stages of evaluation.

INTERPRETATION: There has been a substantial amount of research describing many of the problems experienced by the cancer survivors. This is strongest in the area of symptoms in the period soon after treatment. However, the quality of the evidence is often poor, and some topics have been little examined. We urgently need data on the natural evolution and scale of the problems of cancer survivors obtained from well-designed, large-scale cohort studies and the robust testing of interventions in clinical trials. Given the current financially constrained research funding environment, we suggest areas in which strategic investment might give findings that have the potential to make a major impact on patient well-being in a 5-year time scale.

British Journal of Cancer (2011) **105**, S82–S94; doi:10.1038/bjc.2011.425 www.bjcancer.com

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Keywords: cancer survivors; scoping review; unmet needs; intervention; research priorities

As cancer incidence rises, cancer mortality falls and the population ages, the number of people living with and beyond cancer will continue to grow by more than 3% a year (Maddams *et al*, 2009). Although this figure is a testament to advances in the early detection and better treatment of some cancers, there has been growing concern that the services required to meet the physical and emotional needs of survivors have not been adequately developed. A study from the US National Health Interview Study (Hewitt *et al*, 2003) comparing nearly 5000 cancer survivors with 90 000 people without a history of cancer found that survivors were more likely to report being in poor health and have psychological or functional disability than those without a cancer diagnosis, and

the likelihood of poor health was much higher among those who also had another comorbid condition in addition to their cancer. (Elliot and Corner, 2011).

In the UK and internationally, there have been calls for more detailed consideration to be given to the needs of cancer survivors alongside a desire to discover the most effective ways of meeting those needs (Hewitt *et al*, 2005; Cancer Journey Action Group of the Canadian Partnership Against Cancer, 2008; Department of Health, 2010). For example, in UK, the National Cancer Survivorship Initiative (NCSI) has called for a fundamental shift in the way cancer survivors are supported, moving from a formulaic medical emphasis in follow-up to an approach based on individualised needs and preferences and the promotion of recovery, health and well-being.

Research can have a central role in supporting such shifts, providing the evidence to build a picture of the range and extent of

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problems that cancer survivors face and testing approaches designed to prevent and alleviate those problems. The research reported here was commissioned to support the research work stream of the NCSI.

We aimed in this review to summarise what is known from existing research about the problems faced by cancer survivors and the effectiveness of different solutions to these problems. We also sought to identify areas in which research investment might have an impact on the care of cancer survivors within the next 5 years to inform the future research priorities of the NCSI. The term 'cancer survivor' has been widely interpreted; we have taken this to mean someone who has completed initial cancer treatment and has no evidence of active disease, or is living with progressive disease but is not in the terminal phase of their illness or has had cancer in the past (Macmillan Cancer Support, 2008). We concentrated on the stages of the cancer journey covered by: (1) the period immediately following treatment and (2) the short- and long-term consequences of cancer. Owing to the breadth of the topic area, we used scoping review methodologies. Through the application of this method, we sought to identify what we know, what we do not know and opportunities for research to improve our knowledge of cancer survivorship.

MATERIALS AND METHODS

Scoping reviews 'aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available... [suitable for] ...an area is complex or has not been reviewed comprehensively before' (Arksey and O' Malley, 2005). They are often used to gain a preliminary assessment of potentially relevant literature and its size. Our methods broadly followed those of Arksey and O' Malley (2005). Two separate but linked reviews focussed on (1) problems faced by cancer survivors and (2) the effectiveness of interventions for these problems. In order to make the task manageable in the time available, we searched for, retrieved and rapidly appraised systematic reviews (rather than original publications) sourced from the most common electronic databases (including Medline, EMBASE, Psychlit, PsychINFO, Cochrane Library, CINAHL, Web of Science and British Nursing Index) up to the end of 2009. The reviews were supplemented with more recently published individual studies. Detailed explanations of the methods used can be found elsewhere (Foster *et al*, 2009; Richardson *et al*, 2009; Ziegler *et al*, 2009; Brearley *et al*, 2011).

Review one

The first review focussed on the descriptions of the 'health and well-being' of cancer survivors including physical, psychological, social and practical aspects.

Inclusion and exclusion criteria Reviews (including systematic, comprehensive or other types of literature reviews of research evidence of both qualitative and/or quantitative studies) were included if they were written in English, published between 1 January 2000 and 31 December 2009 and focussed on health and well-being in the acute, sub-acute, long-term and disease-free phases of cancer survivorship. Reviews related to childhood and adolescent cancer were excluded (as they were subject to a different piece of work), as were drug trials and review articles other than research literature reviews (e.g., retrospective data review; overview; review of treatment outcome; review of an individual patient case).

Review two

The second scoping review was targeted at scoping and collating research evidence on the effectiveness of solutions to the problems

cancer survivors faced. Therefore, the focus of this review was on retrieving systematic reviews and randomised controlled trials (RCTs) of interventions for common problems including symptoms of depression, anxiety and fear of recurrence, emotional distress, fatigue and pain and impairments to physical functioning, social functioning (including relationships), work and employment and cognitive functioning.

Inclusion and exclusion criteria Published reviews were included if they were written in the English language, published between 1990 and the end of 2009, included an intervention that had relief of one of the above as its primary aim and conducted using systematic review methods. The searching extended to both pharmacological- and non-pharmacological-type interventions and professional-delivered and self-help-type interventions. We excluded reviews devoted to childhood and adolescent cancer and review articles other than those of randomised controlled trials.

Procedures

Abstracts and titles of review articles considered potentially relevant were selected for further examination. The bibliographic details, keywords, abstracts, website address (where available) of identified articles were imported into bibliographic databases. Relevant reviews were selected for synthesis with reference to inclusion/exclusion criteria.

Data were extracted and summarised using data extraction sheets suitable to the different types of reviews. Each review identified for possible inclusion in the problems in the health and well-being element of the scoping review was awarded a quality score (out of 7) as a broad indication of quality. A review was included if it achieved a score of ≥ 2 . Assessment of the quality of reviews in review 1 was informed by the checklists advocated by the CASP-UK (2011) and Centre for Reviews and Dissemination (2008). Almost all the reviews in the solutions scoping review were high-quality Cochrane-type reviews, and quality screening was not undertaken. Judgments about the study quality of the individual studies included in the reviews were drawn from the commentary available in the systematic reviews. This constitutes a broad assessment of this feature of the research and relies on what we could infer from comments made by the original review authors. Consequently, we only provide a very broad and general indication of whether the quality of the research evidence in relation to each topic was low, medium or high. In terms of the quantity of research contained in the reviews, this could not always be precisely determined, as sometimes review authors (especially in relation to the health and well-being review) did not state explicitly the number of studies they reviewed, but referenced studies throughout the text. Because there was scope for error in counting these, we chose to use approximations and applied a banding system (low, moderate and high amounts of research), and therefore a precise number of studies are not offered (see Table 1 for a summary of criteria used).

To supplement the search for reviews, additional searches to identify primary research papers published after the time frame of the included reviews were performed. This was an extremely time-limited exercise, and we adopted a simple and pragmatic method of focussing on high-quality publications whereby we only included those studies published in journals with an impact factor of more >3 for studies of health and well-being and >5 for studies of interventions.

RESULTS

We included 25 reviews and 61 primary research papers describing problems of health and well-being in review 1, and 49 reviews and 21 primary research papers with respect to solutions in review 2.

Table 1 Criteria used to determine amount and quality of research contained in reviews

Review 1 – health and well-being				Review 2 – solutions			
Amount		Quality		Amount		Quality	
Low	0–15 Studies	Low	Inferred from comments	Low	≤5 RCTs	Low	Inferred from comments made in
Medium	16–55 Studies	Moderate	made in individual reviews	Medium	6–10 RCTs	Moderate	individual reviews
High	56+ Studies	High		High	≥11 RCTs	High	

Abbreviation: RCT = randomised controlled trial.

Bringing reviews 1 and 2 together, the specific topics addressed in detail were: fatigue and physical functioning, pain, sexual functioning, cognitive functioning, general distress, depression, anxiety, social needs and employment, finance and employment/return to work. Tables 2–4 draw together findings in relation to physical, psychological and social dimensions of survivorship in terms of amount, scope and quality of research. Appendix contains a full list of papers included in the scoping review in relation to physical and practical well-being, psychological and social problems, and the systematic reviews of interventions. Review papers are listed in Appendix if they met the initial criteria and were selected and appraised during the data extraction process; however, some do not appear in the Tables 2–4 because of their lack of contribution to the final conclusions and/or because they did not relate to the specific areas we addressed in the combined synthesis (for example, we did not address quality of life in general). Each area is now addressed in turn.

Physical functioning and fatigue

The problem Impairment in physical function has been commonly researched in relation to fatigue. There is strong evidence that cancer survivors experience fatigue soon after treatment, but only modest evidence for increased fatigue in the longer term. There is modest evidence that fatigue is associated with other symptoms such as pain and sleep disturbance and that it impacts quality of life. Most evidence relates to disease-free women with breast and ovarian cancer and survivors of Hodgkin's lymphoma.

Solutions There is a modest amount of research testing interventions for fatigue and physical functioning, mainly patient education, and rehabilitative approaches such as exercise and cognitive behavioural therapy (CBT). The best evidence is for exercise. No clear overall recommendations for treatment can be made.

Pain

The problem The evidence clearly shows that pain is a problem for many cancer survivors and specifically that chronic pain is more prevalent in breast cancer survivors than it is in the general population. Radiotherapy and younger age are predictors. Some cancer treatments may cause pain.

Solutions There is very good evidence that non-steroidal anti-inflammatory drugs and opiates are effective for pain in the general population. There is moderate evidence that these are effective for pain in cancer survivors, but less evidence about how to organise services to effectively deliver these treatments to those who need them.

Sexual problems

The problem There is strong evidence that cancer and its different forms of treatment can have consequences for a

survivor's sexual function. This has been most studied in ovarian, testicular, prostate, bladder and cervical cancer. There is also evidence to suggest that symptoms that accompany treatment-induced menopause are distressing.

Solutions There is limited evidence for the use of drug treatments and mechanical devices to improve sexual function in patients with gynaecological and urological cancers. Psychological and behavioural treatments have been little researched and the findings are inconclusive.

Cognitive functioning

The problem There is some evidence that cognitive dysfunction occurs as a consequence of cancer treatment and affects quality of life, but much of the evidence is limited to women with breast cancer. We need more understanding of the incidence, course and effect of alterations in cognitive function in cancer survivors.

Solutions We did not find any reviews of RCTs of interventions specifically intended to address cognitive impairment.

Employment, return to work and finance

The problem This important problem has received little attention from researchers. We have a reasonable understanding of the issues and problems people confront as they try to return to work, and there is good evidence that those who have survived cancer are more likely to be unemployed than the general population. There is also good evidence that those who have head and neck cancer do a job that involves manual labour and perceive their work environment to be unsupportive are less likely to return to work. More understanding is needed of the effect of different types of cancer treatment, different types of cancer and other factors on return to work.

Solutions No evidence on the effectiveness of interventions was located. The application of vocational rehabilitation in other fields could be explored to identify potential approaches.

Emotional distress

The problem There is very good evidence that cancer survivors suffer from increased distress during and soon after active treatment, but less evidence for its occurrence in long-term survivors. However, there is clearly a subgroup of long-term survivors (for example, those with actual and fear of recurrence) who have high levels of distress that merit help. Most at risk are women, those with a lower socioeconomic status and those with disabling and disfiguring cancers such as head and neck cancers. Most of the evidence is limited to women with breast cancer.

Solutions There is a large amount of poor-quality research evaluating a range of psychological interventions such as

Table 2 Summary of findings from scoping reviews: physical problems

Problems					Solutions		
Issues	Amount of research ^a	Quality of research ^b	Scope	Conclusion	Amount of research	Quality of research	Scope
Fatigue	High	Moderate	Ovarian, Hodgkin's disease, breast and mixed cancers	There is strong evidence that cancer survivors experience fatigue soon after treatment, but there is a need to explore its prevalence among the long-term survivors and its association with other physical symptoms (i.e., pain and sleep; Appendix refs 8, 4, 123 and 141)	Moderate	Moderate	Mainly mixed cancer samples and early survivorship
Physical functioning/functional impairment	Moderate	Moderate	Mixed cancers, mainly in relation to older cancer survivors	Moderate evidence of the side effect of treatments on patients' physical performance. Older cancer survivors have poorer physical functioning than non-cancer. More information is needed from younger survivors (Appendix refs 8, 45 and 84)	Low	Low	Mixed samples
Pain	Moderate	High	Mixed cancers, mainly in relation to fatigue	Moderate amount of evidence that cancer survivors experience pain, mainly as a result of the treatment – but evidence is mainly related to fatigue. 2–5 Years for all cancers (Appendix refs 8, 84, 123 and 141)	High	Moderate	Mainly mixed cancer samples and mixed stages of survivorship
Sexual functioning	High	Moderate	Ovarian, testicular and mixed cancers	Strong evidence of the consequences of cancer treatment for survivors' sexual function. However, more evidence is needed on how survivors cope up with these difficulties. Ovarian and testicular cancers <2 years if good quality research. Other cancers 2–5 years (Appendix refs 45, 59, 70 and 84)	Low	Low	Gynaecological and urological cancer samples at various survivorship stages
Problems					Solutions		
Issues	Amount of research ^a	Quality of research ^b	Scope	Conclusions	Amount of research	Quality of research	Scope
Cognitive functioning	Low	Moderate	Ovarian cancer only	There is some evidence that some treatment for ovarian cancer might affect cognitive function; more information is needed about this problem among other cancer survivors and more understanding of the incidence and course of this problem (Appendix ref. 84)	—	—	—
Work/employment	Moderate	High	Mixed cancers	There is evidence of substantial survivors' needs, but little evidence of assessment of risk, and little separation of personal (e.g., early retirement) vs medical (disability, body image) factors in predicting unemployment. There is an (unquantified) need for support for employers (Appendix refs 36, 132 and 59)	Low	Low	Breast cancer
Finance	Low	Moderate	Mixed cancers	Very little evidence of the financial consequences of cancer. There is a need for more understanding how cancer and its treatment affect the financial situation of the survivor and his family (Appendix ref. 59)	—	—	—

Abbreviation: CBT = cognitive behavioural therapy; RCT = randomised controlled trial; TENS = transcutaneous electric nerve stimulation. ^aA scale ranging from Low to Moderate to High has been used to provide a broad indication of the amount of research described in the reviews. ^bTerms such as Low, Moderate, High and Unclear have been applied to give a broad indication of the quality of research inferred from the comments made in original reviews.

Table 3 Summary of findings from scoping reviews: psychological

Issues	Problems			Solutions		
	Amount of research ^a	Quality of research ^b	Scope	Conclusions	Amount of research	Quality of research
Depression	Moderate	Variable	Mostly women – mostly breast and ovarian cancer; men – prostate cancer	Moderate amount of evidence that cancer survivors experience depression – particularly those who are younger, have more advanced disease, more physical symptoms – but evidence is mainly focussed on women with breast cancer (Appendix refs 5, 17, 47, 51, 84 and 146)	Moderate	Moderate
Anxiety	Moderate	Variable	Mostly women – mostly breast and ovarian cancer	Overall similar levels of anxiety to general population – moderate evidence that some cancer survivors (up to 30%) experience high levels of anxiety. Moderate evidence for a relationship between younger age, being diagnosed with more advanced disease, more physical symptoms and shorter time since diagnosis with increased levels of anxiety. Inconclusive results on the role of anxiety in recurrence and survival outcome. Evidence is mainly on women with breast cancer (Appendix refs 5, 47, 51 and 84)	Low	Low
General distress	Moderate	Variable	Mostly women – mostly breast and ovarian cancer	Low to moderate amount of evidence that cancer survivors have similar levels of general distress to healthy controls. Distress is associated with poorer QoL, lower SES, and head and neck cancer survivors may be more vulnerable to distress. Evidence mostly on women with breast cancer (Appendix refs 5 and 51)	Moderate	Low
Fear of recurrence	High	Variable	Mostly women – mostly breast and ovarian cancer	High amount of evidence that fear of recurrence is a concern for cancer survivors and their families. Evidence mostly based on women with breast cancer (Appendix refs 17, 51, 84 and 142)	—	—

Abbreviations: CBT = cognitive behavioural therapy; QoL = quality of living; SES = socioeconomic status. ^aA scale ranging from Low to Moderate to High has been used to provide a broad indication of the quantity of research described in the reviews. ^bTerms such as Low, Moderate, High and Unclear have been applied to give a broad indication of the quality of research inferred in the reviews.

Table 4 Summary of findings from scoping reviews: social

Issues	Problems			Solutions		
	Amount of research ^a	Quality of research ^b	Scope	Conclusion	Amount of research	Quality of research
Social needs (function)	Low	Unclear	Mixed, mainly breast cancer	Low evidence that levels of social functioning similar in cancer survivors to control groups. Evidence mainly based on women with breast cancer (Appendix refs 51 and 143)	Moderate	Moderate
Social support	Moderate	Unclear	Mixed, mainly breast cancer	Moderate evidence that perceived social support is positively associated with mental well-being, less distress and higher levels of QoL. Inconclusive evidence that social support is linked to survival from breast cancer. Evidence mainly based on women with breast cancer. Breast cancer 2–5 years if good quality research. Other cancers > 5 years (Appendix refs 5, 16, 17, 47, 51, 95, 102, 118 and 146)	—	—

Abbreviations: RCT = randomised controlled trial; QoL = quality of living. ^aA scale ranging from Low to Moderate to High has been used to provide a broad indication of the quantity of research described in the reviews. ^bTerms such as Low, Moderate, High and Unclear have been applied to give a broad indication of the quality of research inferred in the reviews.

counselling and group therapy. The best evidence is for CBT. There is evidence of temporary benefit only from complementary and alternative medicines. Much of the research is flawed by attempts to treat all patients rather than confining the intervention to those with distress. No clear overall recommendations for treatment can be made at present.

Depression

The problem There is good evidence for a significantly increased rate of depression in cancer survivors during and soon after active treatment. However, there is less evidence concerning long-term survivors; persistent and recurrent depression is likely to be a problem for an important minority. Those most at risk are people who are younger, female and who have more advanced disease. Much of the evidence is limited to women with breast cancer.

Solutions There is good evidence that antidepressant drugs, CBT and complex treatment models such as collaborative care are effective for depression in the general population. However, there is only moderately good evidence that antidepressants, CBT and collaborative care are effective in reducing depression specifically in cancer survivors. We do not know how best to identify depression in long-term survivors.

Anxiety

The problem There is some evidence for increased anxiety after treatment; this is connected with anxiety about check-ups and medical follow-up appointments. There is little evidence concerning long-term survivors, but anxiety, especially about recurrence, is a problem for a proportion. Those most at risk are younger, have more physical symptoms, are closer to point of diagnosis and have more advanced disease. Most of the evidence is limited to women, particularly those with breast and ovarian cancer.

Solutions There is limited evidence about effective interventions for anxiety. Cognitive behavioural therapy is likely to help, but has not been adequately evaluated. Aromatherapy massage may bring some short-term relief. Exercise may also have a role.

Social needs

The problem The social impact of cancer and the influence of social support on outcomes such as emotional well-being and quality of life have been studied mainly in breast cancer. There is modest evidence that perceived social support is positively associated with well-being and quality of life. The psychosocial implications of cancer survivorship for family members have not been well studied. Evidence to date suggests that distress in family members persists over 5 years following diagnosis.

Solutions There is modest evidence that support groups have a positive effect on marital satisfaction and sexual relationships, and some evidence that interventions targeted at spouses might improve marital relationships. No other clear recommendations can be made about approaches that might prove effective with respect to meeting social need.

Quality of the primary research

Although a scoping review does not offer a detailed critique of the methods adopted or study quality, through the process of conducting our review we were struck by a number of recurrent methodological problems that were frequently highlighted by those conducting systematic reviews. These shortcomings are as follows:

Research questions A key and all too common problem is the lack of precision in the research questions that are asked (e.g., the effect of a vaguely specified intervention on a wide range of vaguely specified outcomes). Such studies, not surprisingly, produce only vague answers.

Samples studied The origin of samples is sometimes poorly described and they are often not representative of the population studied. Most research has been carried out on women with breast cancer; other cancers have been neglected. There is little research into the needs of minority groups and certain cancers, such as lung and the less common cancers. Most study samples are simply too small to give robust results.

Measures A wide variety of measures have been used, with little consistency between studies, making the combination of data across studies problematic.

Study design A common criticism is that studies are methodologically weak and subject to multiple sources of bias, which may make results unreliable. Another major problem of design is the lack of long-term follow-up, both in studies of need and of interventions.

Interventions The interventions evaluated have often been poorly characterised and may not be of a form that could realistically be implemented in practice.

Interpretation

The research evidence is surprisingly limited. We have some knowledge of the prevalence and nature of depression, pain and fatigue in cancer survivors. We know much less about cognitive and physical impairment, employment, financial well-being and relationships. Even where we have evidence, it is mostly of only moderate quality, is most often focussed on breast cancer and almost exclusively on the early phase of survivorship. We have good evidence of the effectiveness of treatments for pain, and moderate evidence for fatigue and depression, but not for other symptoms. Interventions based on rehabilitative and self-management approaches remain in the early stages of evaluation. Our lack of knowledge about how to address the problems of cancer survivors is compounded by a lack of research into how to implement interventions as part of routinely offered programmes of care. We certainly need more research if we are to address the problems of cancer survivors more effectively.

Table 5 Future 'best buys' for research investment in key areas of cancer survivorship

Issue	Time frame		
	Less than 2 years	2–5 Years	5 Years plus
Fatigue and physical function	(1) Pilot studies of simple, feasible methods of identifying fatigue in survivors; (2) studies of barriers to implementing treatments such as guided self-help, telephone delivered treatment based on CBT principles and exercise	Large, multi-centre studies of fatigue management with adequate follow-up period that integrates screening and treatment	Prospective cohort studies with age-matched comparisons to study course of fatigue and physical function in relation to factors such as cancer site, treatment history and stage
Pain	(1) Secondary analysis of existing data on prevalence of pain and risk factors in survivors; (2) pilot studies of simple and feasible methods of identifying pain in survivors; (3) studies of the barriers to implementing pain management models such as collaborative care	Large trials of interventions based on feasible models of delivery that integrate screening and treatment systems such as collaborative care	Cohort study to identify risk factors for long-term pain
Sexual function	Surveys of prevalence and psychological and social associations	Feasibility studies of integrated systems of assessment and management	Large trials of interventions
Cognitive function	Prevalence and risk factor studies of cognitive impairment and its association with functional and psychosocial ability	Pilot studies of methods to identify and intervene with those who are suffering from cognitive impairment	Large trials of preventative and treatment interventions
Employment, finance and return to work	(1) Theoretical and modelling work to establish the transferability of vocational rehabilitation approaches used in other contexts to cancer survivorship; (2) In-depth studies to understand the financial effects of cancer; (3) Studies to evaluate the best way to educate and support employers to support cancer survivors whilst returning to work	Well-designed pilot trials of feasible methods of intervention	Large, prospective cohort studies to identify factors that impact on return to work and vulnerable subgroups and large-scale intervention studies
Emotional distress	(1) Secondary analysis of existing data on long-term outcome; (2) Well-designed pilot trials of feasible methods of intervention	Large trials of interventions based on patient education including guided self-help and telephone delivered treatment based on CBT principles	(1) Large, prospective cohort studies of mixed cancer groups; (2) Studies to improve understanding, identification and management of distress in men and BME groups
Depression	(1) Secondary analysis of existing data on prevalence and risk factors in long-term survivors; (2) -pilot studies of simple feasible methods of identifying depression in survivors in hospital and primary care; (3) Studies of the barriers to implementing established treatment models such as collaborative care	Large trials of interventions based on feasible models of delivery that integrate screening and treatment systems and have an emphasis on primary care provision such as collaborative care	Studies to improve understanding of how we can identify and manage depression in men and BME
Anxiety	Secondary analysis of existing data to determine prevalence of anxiety in the long-term and associations with fear of recurrence	Well-designed pilot trials of feasible methods that combine detection and intervention suitable to address minor, modest and severe anxiety and interventions for fear of recurrence	(1) Large-scale, multi-centre trials of simple feasible interventions; (2) Cohort study to identify risk factors for persistent anxiety
Social needs	(1) Exploratory studies to identify forms of social support that might prove effective and factors that dictate whether families do or do not seek support; (2) Secondary analysis of existing data on long-term outcome and moderating factors	(1) Pilot trials of feasible methods of intervention to minimise or manage the effect of cancer on relationships; (2) Studies of the effect of a diagnose if cancer on relationships	Cohort studies of mixed cancer groups that include family members. More understanding of how to identify and manage those who perceive they have unmet need, especially in those with cancers other than breast cancer and in BME and other disadvantaged groups

Abbreviations: CBT = cognitive behavioural therapy; BME = black and minority ethnic groups.

Limitations of the review

Our review of this large area of research is necessarily limited in scope by the time and resources available to complete it. Primarily, reviews of studies rather than original research reports were examined. Where we did search for individual studies after the publication date of the most recent reviews, we confined this exercise to journals that had a particular impact factor. This may have impacted our findings, particularly judgments about the amount of research available in relation to an individual topic, as some of the journals that publish studies in this field (e.g., *Supportive Cancer Care*, *Cancer Nursing* and *European Journal of Cancer Care*) had not achieved the impact factor selected to merit inclusion. There was a focus on the more common problems and widely used treatments for them to the neglect of other topics. For example, we did not address the organisation and delivery of care, information and support (e.g., the process of care planning and methods of care delivery), the impact on families and the lifestyle dimensions of survivorship.

Setting priorities for future research

Identifying research priorities is not as simple as it might first appear. Critically, it is not as simple as identifying the 'gaps' in the evidence described above. The presence of 'gaps' in evidence may indicate an area difficult to research that would need many years of investment to address. Furthermore, even in areas where we have the information we need about a problem, including possible solutions, research may still be needed to work out how to implement these solutions in everyday practice.

It is also important to note that research takes more than money; although money is essential, it also requires skilled researchers with an interest in the question to deliver high-quality answers. Such people remain in very short supply for many of the questions posed here, despite this being recognised some years ago (National Cancer Research Institute, 2004).

Scoping reviews, especially those designed to identify research gaps, are often enhanced, and results can be made more useful if policymakers, clinicians and service users contribute to the work in the form of consultation (Arksey and O' Malley, 2005). Our study also included a consultation and prioritisation element (details can be found in (Armes et al, 2009)). Contributors to this exercise included researchers, commissioners and consumers of survivorship research in the UK. The top five priorities to emerge from a survey and consensus event included: studies to understand

the epidemiology of needs; methods to identify and manage consequences of cancer and treatment; the organisation and delivery of care; psychosocial issues; and informal carers and families (Armes et al, 2009). The consultation served to inform and, in some cases, validate the findings from the scoping review. For example, the strong desire for research to determine optimum ways to organise and deliver services emerged in this way.

The shrewd investor in research might therefore be well advised to fund areas of research where not only are there 'gaps' in evidence about important topics but where there is also a likelihood of the findings being 'implementation ready' in a reasonable time scale and for which there are existing groups with a track record of delivering high-quality research. These represent what we refer to as 'best buys' for research investment and are collated in Table 5. We use periods of less than 2 years (very short term), 2–5 years (medium term) and greater than 5 years to qualify these recommendations. These take into account the stage the research has reached, and the relative complexity, scale and length of time it might take to undertake it. We would suggest that funders do not spend limited funds on yet more small-scale research studies unless these comprise a development phase of more significant, large-scale research. Rather, we need well-funded, coordinated research efforts executed by skilled research teams working in partnership with clinicians and cancer survivors. Priorities should be (1) large-scale prospective cohort studies that sufficiently describe needs of long-term survivors and to predict those most at risk; (2) robust randomised trials of well-specified 'delivery ready' interventions; (3) research to determine the most effective and efficient ways to organise care.

ACKNOWLEDGEMENTS

We thank the COMPASS and CECco administrators, Susie Edwards and Anne-Marie McDonnell, for their support during the conduct of the study and Liz Neilly and Linda Robertson, librarians at the University of Leeds and University of Southampton, respectively. We also thank those who contributed to the survey and consensus event about research priorities and Jim Elliott and John Neate, Joint Leads of the National Cancer Survivorship Initiative research work stream, for their guidance. The research upon which this paper is based was funded by Macmillan Cancer Support on behalf of the Department of Health and the National Cancer Survivorship Initiative. The views expressed here are those of the authors and not necessarily those of Macmillan Cancer Support or the Department of Health.

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Appendix

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